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LIH-MEI LIAO is a clinical psychologist who works with women born with conditions that are associated with atypical reproductive-genital development. Clinical management of some of these conditions remains extremely controversial. Historical precedent, medical power and social intolerance produce a context that continues to centralise invasive surgery as the solution to problems of sexual anatomy and identity. Lih-Mei works as part of the multi-disciplinary team at the Middlesex Centre at University College Hospital (UCH) in London. Following her presentation at the 'What's different about sex?' conference, I met with her to find out about the trials and tribulations of her work, in particular her input in relation to vaginal reconstruction.

The context

CB: Let's start by describing the setting in which you work, I guess the psychology that you do is a specialism within an already specialist tertiary service?

LML: Our clinic carries out investigations, treatment and research relating to atypical reproductive-genital development associated with a number of congenital conditions. These conditions have recently been termed 'disorders of sex development' (DSDs). Some DSDs are associated with both male-typical and female-typical or ambiguous reproductive-genital characteristics and have been referred to as 'intersex', paediatric management of which is an area of controversy. In societies where surgical techniques are available, the majority of children whose external genital appearance is not sufficiently sexed tend to be socially and surgically assigned female in childhood (see *The Psychologist*, August, 2004, for a brief overview). This is partly why our clinic is based in Women's Health. Our team offers services to people from about mid/late teens right up to late midlife. I try and meet all of our new patients (and their families where appropriate), thereafter patients self refer to me.

CB: What got you interested in this area?

LML: I used to work in reproductive endocrinology and saw women with different problems including polycystic ovary syndrome (PCOS)¹. I was interested to note some very extreme reactions to the unwanted hair growth associated with PCOS. Clients told me that they felt unfeminine, abnormal and undeserving of relationships; the term 'freakish' was often used. I remember on one occasion, a young woman asked if removal of her ovaries would eliminate the problem of hair growth. As it happened it would not have helped, but the sacrifice she was prepared to make in order to 'normalise' was significant. People seem to take entirely for granted that we are all mutually exclusively female or male. Where that boundary is blurred by characteristics deemed to belong to the 'opposite' sex, some individuals can become extremely preoccupied with fixing the problem. The fear of repercussions – should they fail to repair the damage – was striking. In those days I was occasionally referred clients (women and men) diagnosed with rarer medical conditions, some of which were

associated with what I have come to know as intersex. Their issues highlighted for me the problems of a belief system that recognises only two mutually exclusive sexes.

CB: How has your work developed over time?

LML: Members of UK intersex forums had pressed hard for a multi-disciplinary service that is designated to DSDs. They documented the difficulties that their members had had in finding good care. Without a multi-disciplinary centre of referral, it would have been difficult to learn from patients and improve our knowledge and skills. So from the late 1990s, colleagues and I have been offering a multi-disciplinary 'one-stop' service for women. In the earlier years, I saw a lot of women aged between their 30s and 50s who had felt damaged by the way their condition had been managed. Some of these women had had their diagnosis withheld from themselves, and some had been engaged in investigations, treatments and medical photography without their consent. It was important for me to offer support. I also started to formulate research themes. In more recent years I have seen a lot more adolescent and young women. Some of these women have survived birth conditions that used to have a high mortality rate, such as anorectal malformations². For these women, life preserving operations would have been carried out throughout their childhood. Now that they are adults they aspire to relationships like everyone else. We also see patients who present for investigations because their periods have not started and are then told that they had no uterus or vagina. In our service, vaginal reconstruction is a key intervention for a number of DSDs. Reconstruction is relatively common as it is also applicable to some women with pelvic cancers or injuries (e.g. as a results of child-birth or accidents). I have put a lot of energy into working closely with gynaecological and urological surgeons and nurse specialists.

Importance of psychology in vaginal reconstruction

CB: What is your sense of the hope and/or fears of your clients regarding vaginal reconstruction? How do they see your role?

LML: Understandably, the greatest hope is a one-off surgical fix. Not everyone is enamoured with psychology, which involves active engagement with some very perplexing and distressing issues. But we know from the literature and from experience that psychological difficulties often surface after surgery (see Boyle *et al.*, 2005). For example, the surgically constructed vaginal volume often needs to be maintained by the patient through the use of dilators. Where women have avoided engaging with the psychological issues, they sometimes cannot find a capacity to follow the dilation regime afterwards. This places them at risk of having to undergo more operations.

CB: So what do you do to help, how do you see your role?

LML: I work at all levels – with the individual client, couples or families. I also run groups and workshops and I consult to the team regularly. An example of what I do is the development of a nurse-co-ordinated protocol for supporting women in their effort to dilate their vagina in preparation for intercourse – in order to try and avoid (more) surgery. The pilot work that led up to the protocol had highlighted for us the negative emotional impact that a dilation regime could have on some women (reported in Liao *et al.*, 2006). Our protocol makes use of basic ideas from clinical psychology to enhance treatment adherence but with much broader aims than changes to vaginal size. Women who are considering dilation now have the opportunity at different stages to explore their thoughts and feelings about the treatment and their diagnosis. They are invited to explore their hopes and fears about relationships and intimacy and to learn to value individual choice in sexual relating.

facilitate willing clients to experiment with different positions and standpoints and see what they come up with and ultimately to identify optimal solutions for themselves.

CB: You have spoken about working with clients who may have different ideas to your own, but how does that work with your colleagues?

LML: Medics (and psychologists) are influenced by mainstream, heteronormative ideas about sexuality. That is to be expected. For practitioners these ideas are further reinforced by patients who seek their help. In my context, the majority of women presenting with a smaller than average vagina – all age and ethnic groups, single and partnered, lesbian and straight – opt for some form of genital reconstruction. So it is easy for clinicians to maintain the belief that it is natural that all women ‘need’ a vagina to ‘have sex’. But because these ideas can be limiting, even damaging – for example, where a woman ends up having repeat operations with diminishing returns, I do claim a role in helping the team to unpack some of the imperatives.

CB: I’m interested in how you tackle those challenges in practice ...

LML: I think a most important lesson that I drew on in my systemic psychotherapy training was to ‘join with’ the system/context. This has been a useful mantra that has enabled me to have a curiosity about the different positions that people may take. For example, I learned about surgery, even went into theatre to observe how operations were done. After all, my surgical colleagues knew nothing about psychology at first yet implicitly accepted its potential; the least I could do was to learn more about their work and their contexts. At times my colleagues are baffled by the criticisms directed at health professionals, so I might try to put the issues across in a more accessible way. Joint consultations also provide opportunities to model a more exploratory consultation style or different vocabularies.

In collaborative research, I have suggested constructive alternatives to the

emphasis on functionality of female genitals. In time, alternative conceptualisations develop and new vocabularies are tried. Of course, these activities would not have been possible had my colleagues been less open minded. Risks of surgery are now very explicitly communicated to patients and significant others. Individual sexual potential and choice are now emphasised instead of heteronormative sexual performance. We are also more likely to say ‘genital intercourse’ rather than ‘sex’. These small but significant changes have evolved without any finger-wagging, which would have been demeaning for my colleagues and for me. An atmosphere of mistrust, mutual resistance and mutual undermining amongst ourselves would not be very helpful to the people that we serve.

The future of psychology in this area

CB: How would you like to see psychology developing in this area?

LML: We desperately need a strong health care psychology in this field. In the past, psychological influence in management of ambiguous genitalia was dominated by the so-called optimal gender policy developed by psychologists in the US. This did not necessarily lead to good psychological care, rather justified surgical correction of the genitals in infancy and childhood in the interests of stabilising gender identity and psychological functioning. That line of reasoning is no longer taken so seriously (although childhood genital surgery has continued) and in general, there is broad agreement on the importance of good psychological care in future DSD management. However, the detailing of actual service delivery (e.g. its theories and methods) is not yet there.

CB: And is there much psychological literature to help with that?

LML: There are valuable critical analyses by psychologists (e.g. Kessler, 1998) and I try hard to ensure that these perspectives are taken on board in my practice. My own contributions to the literature have mainly been in highlighting the personal costs of

normalisation through surgery and in exploring alternatives with my team. I would quite like to exploit the mainstream health care psychology literature more, to maximise clinical effectiveness and to do more evaluations of psychological interventions. For years I have been fascinated by the work of James Pennebaker and his colleagues on the impact of emotional disclosure on health (see, for example, Pennebaker & Seagal, 1999). This work and plenty of good psychology has yet to be creatively exploited in my field. I am confident that within a critical-reflexive formulation, many methods/techniques have the potential to generate a greater range of solutions, improve well-being and reduce treatment complications.

CB: What about research? Do you see that as part of your role?

LML: Research with adults will influence paediatric management in the long term. For example, research that shows that childhood genital surgery is associated with impaired sexual function in adulthood will challenge childhood surgery as a routine response to ambiguous genitalia (e.g. Minto *et al.*, 2003). At the very least, clinicians will have to be much more careful about how they advise parents of intersexed children about surgical management. If in future there is more evidence on the negative effects of childhood surgery, more parents may be willing to assign sex whilst delaying surgery. But cross-sectional research with adults will not replace the need for a prospective, longitudinal cohort study to systematically follow-up children presenting with ambiguous genitalia. It is, of course, unethical to randomise children into surgery and non-surgery groups so this would have to be an observational study. Psychological expertise would be crucial for that work. In the years to come, this kind of work will tell us more about what might constitute optimal clinical management throughout the lifespan and how psychology could contribute to that.

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Details of several intersex peer support forums:

UK:

www.medhelp/www/ais; www.ahn.org.uk

International:

www.isna.org; www.ipdx.org

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